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ABSTRACT

Based upon 15 interviews, the paper discusses specific educational and social problems as perceived by nine brain injured learners (14-24 years old), their teachers, families, and peers. Interview excerpts illustrate executive functions of self-awareness, self-evaluation, and self-monitoring; the effects on families; and student difficulties in quantitative subject areas. Recurrent themes are noted, including feelings of disorientation, debilitating effects of negative teacher attitudes, and the existence of innovative problem solving approaches on the part of the brain injured students. (CL)

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Head Injured Learners: Facilitating the Education/Social Adjustment of Traumatically Brain Injured Learners in Academic Settings

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HEAD INJURED LEARNERS:

Facilitating the Education/Social Adjustment of Traumatically Brain Injured Learners in Academic Settings

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This paper was presented at the annual meeting of the Council for Exceptional Children, Anaheim, 1985.

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FACILITATING THE EDUCATIONAL/SOCIAL ADJUSTMENT OF TRAUMATICALLY BRAIN INJURED LEARNERS IN ACADEMIC SETTINGS

ABSTRACT: *Brain injured students experience difficulty upon returning to academic settings. This paper, based upon fifteen interviews, discusses specific educational and social problems as perceived by brain injured learners, their teachers, families, and peers. Sources of potential help are described, and suggestions to facilitate communication between rehabilitation personnel, families, and educators are presented.*

An increasing number of brain injured young people, after leaving hospitals and rehabilitation facilities, return to schools and colleges. Success in these settings is dependent upon social as well as academic skills. Restricted ability to function appropriately in either area leads to failure, rejection, and exclusion.

At present, there appears to be little information in the rehabilitation and educational literature that deals specifically with the academic adjustment of traumatically brain injured learners. There is, however, an increasing body of literature pertaining to the effects of frontal lobe damage on behavior.

Lezak (1984) maintains that

> The structure of the brain and the mechanics of head trauma - particularly in motor vehicle accidents - make the frontal lobes very vulnerable to accidental damage...
> ...Frontal lesions can interfere with normal behavior in a number of ways: A concrete attitude creates literal and stimulus-bound thinking resulting in impaired judgment and defective problem solving. Executive disorders may appear as diminished or absent initiation or motivation, as defective capacity to plan and organize activity, as inability to carry out activities fully or effectively, as impaired self-monitoring or self-regulation, or - most usually - as some combination of these dysfunctional capacities. Emotional disturbances characterized by flattened affect, loss of social sensitivity, heightened impulsivity, and irritability or anger outbursts are also common concomitants of frontal lobe damage.

If it can be assumed that intact executive abilities are requisite to success in academic settings, it becomes important to assess these abilities in brain injured learners. Lezak (1983) has written about the complexity of evaluating executive function with formalized procedures:

> The problem for clinicians who want to examine the executive functions becomes how to transfer goal setting, structuring and decision making from the clinician to the subject within the structured examination. Only a limited number of established examination techniques give the subject sufficient leeway to think of and choose alternatives as needed to demonstrate the main components of executive behavoir.

Lezak also observed:

> Cognitive defects associated with frontal lobe damage tend to show up most clearly in the course of daily living and are more often observed by relatives and co-workers than by a medical or psychological examiner in a standard interview.

INVESTIGATING THE PROBLEM

Through their dual roles as educators and the parents of a brain injured son, the authors became acutely aware of the difficulty faced by students returning to school following traumatic brain injury.

In an attempt to clarify the types of problems encountered by these students, the authors interviewed an available sample of brain injured students, their parents, teachers, and peers. This was not a formal study, but rather an anecdotal survey. Information was obtained from fifteen subjects regarding nine traumatically brain injured young people, age fourteen through

twenty-four, eight males and one female. Six of the students were attending or had completed high school, while three were in college. They ranged from one to nine years post trauma. All nine experienced educational and/or social difficulties.

In order to communicate results of these informal interviews, selected excerpts from audio tape transcriptions are included in the discussions that follow.

The first excerpt illustrates the executive functions of self-awareness, self-evaluation, and self-monitoring. It is taken from a discussion between the authors and their son Jay as they talked together around the kitchen table. Jay is twenty-three years old. He is nearly five years post trauma. In the summer before he was to enter college, while riding his motorcycle home from work, Jay was hit by a drunk driver. He was in a coma for three months, spent five months in the hospital, followed by four and one-half years in rehabilitation and extended care facilities. Because of severe physical disabilities he has received continuous and extensive physical and cognitive therapy. Jay demonstrated his self-awareness and self-monitoring as he described the problems he now experiences.

C: So what kind of problems are you having learning?

J: Learning? Well mainly, for me personally, I'm sure that memory is a large cognitive asset. Well, I mean, whatever word it is.

D: What do you mean?

J: Mmm--I mean that's a--that's a wrong doing--or a--I'm trying to think of a quotation meaning a let--a let-back.

D: Are you trying--are you having trouble finding the word--now--that you want?

J: Yes. That is a--that is another struggle I have. I have trouble with word selection.

D: Mm hmm. You said that your learning--that your memory is an "asset," which would mean that it's a strength.

J: I'm sorry. That's my--part of my problem also--is my--a--confusion of complicated words such as that. I'm not saying necessarily that the word "asset" is a complicated word, but just for the common mind--or--

D: (interrupting) What did you want to say? You were starting to run off and ramble there.

J: Oh. That's my--one of my major problems is that I do ramble on too darn much.

D: And you know that you're doing that?

J: Well, I do not know it right at the time, but boy it sure shows up like on tape recorders.

D: You mean when you listen to yourself?

J: Yes.

D: Well, how do you know when you--when you are rambling then? Because you don't very often listen to yourself on a tape recorder.

J: I--a--well--sometimes I can--what I--what I do--key--what I personally do--for a key pointer--I look at--I always watch my listener and watch his vision. You know, whether he's looking at my mouth--or the the floor--or even behind me or someone else.

D: (laughing)
So--so--what does that tell you? Like if I were looking at the floor while you were talking, what would that mean to you?

J: That would mean that you were either getting bored or you're (laughing) wondering about whether you had over--overpaid the floor washer. Simple as that.

D: One of those two. Okay. So what's happening now?

J: Mmm--please refresh my mind.

D: Can you refresh your own mind?

J: Aa--I think that is a large cognitive difficulty I have in--my--memory deficit (finger snap) short term always I mean I have a very extensive long term memory. Like I can remember back when I was little. But that is not implying right now.

D: Yeh. So--short term memory is hard. Finding the right word is hard.

J: Yeh. Mm hmm.

C: Have you learned any technique that helps?

J: Mmm. Yeh. To listen to my own wording as I say it. And kinda--if I'm aware of it, I watch my other--the people listening me--watch their reactions and also their wording--uh huh.

D: O.K. So you watch somebody--so what they say and how they look lets you know if you're--

J: Exactly--exactly--their reactions and things like that.

D: O.K. So when you know that--from their reaction--that you're going on too long, can you change it?

J: Um--well--yeh. What I do then is I--I might hafta ask to be rephrased on what I had just said--my god,--but that doesn't happen much to--too darn often--but I can think of key wording which I say--I personally do say--in a sentence describing--or speaking of some particular subject--

D: (interrupting)
What question did I just ask you? What question are you answering now?

J: (laughing)
You got me there!

Some of Jay's self-awareness is his own. Some has been carefully taught. Though he has learned methods of self-monitoring, he is not always able to recognize his difficulties or to correct the ones that he does perceive.

There is a great deal of variation in the amount of self-motivation which exists following traumatic brain injury. Assessment of motivation is difficult. Later in that conversation Jay described the part of himself which wants to learn.

C: Jay, if you went back to school now, what do you think would be the hardest for you--for learning?

I don't mean what subject, but what parts of the school environment--of the activities--

J: Mm

D: If you went back to high school--

C: If you went back to high school, what would be the toughest?

J: Mm (sigh)
Well, I think that something--something which did require much remembrance of--or memory of--like certain wording I don't--I don't mean speech, but words.

C: Mm hmm

D: Like what?

J: Like government--or--

D: The word "government" or the class Government?

J: Class.

D: The class would be hard for you.

J: Well, yeah. At higher level it would be.

C: Because of memory problem.

J: Well yah--and also--just--god-- I mean my injury has not changed my total mind, Dad. My god, there is still a small--little--Jay running--running around in there---

C: (laugh)
D: "A little Jay running around in there?"

C: Yeh, we've been trying--

J: saying "out, out--I want out--help me--please."

C: (laugh)
D: What--what--what little Jay is that? The little Jay that used to know something? Or the little Jay that used to be able to study? What little Jay are you talking about?

J: Mmm. Well, the little Jay who <u>wants</u> to know.

D: Who wants to know.

C: I'm glad he's in there.

J: Boy, so am I.

D: Yeah.

J: Gosh.

C: What does he want to know?

J: How to--wait--please do not let me sound so darn professional--but how to perfect thou self--er myself. How to--I mean--how to perfect himself.

C: Hmm.

D: Can you be more specific than that?

J: How to better--a--meaning ways in which to learn--easier ways--no, I do not mean that. I mean the ways that work.

D: O.K. So the Jay in there who's still running around--who still wants to learn--is saying "help me find the ways that will work, cause I'm still in here trying to learn."

J: Yeah.

That was Jay's first mention of "the little Jay" inside himself. His emotional appeal was not for an easier way to learn, but for a way that works. Like many who are brain injured, Jay could "talk a good game" even before his accident. Now, despite his genuine desire to learn, and many people's attempts to help find better ways to learn, he is not always able to carry out his own good intentions.

The next three excerpts are taken from a taped interview with the mother of a fourteen-year-old brain injured boy. He is two years post trauma and now attends high school in a small Indiana community. During the interview his mother demonstrated her need for understanding when, for ninety minutes, she poured out the story of her son's difficulties to two people she had not previously met. Often she was describing impaired executive functions. She did not know or use the term, but was living with the resulting behaviors. She told of her son's inability to stop an activity and change tasks, his failure to initiate tasks, and how those factors affect their relationship.

Ms. X: It just seems like everything he does now he tries to go overboard with. To me it seems that way, anyway.

C: More competitive than he was--is that what you're saying--or excessive?

Ms. X: I think, yeah, everything it--seems--anything he's really wanting to do--like if he gets a model or something--if it's something he likes--he'll stay up--he'll maybe stay up all night trying to finish that. He can't--he can't seem to stop and say "Well, I'll do this later--I can--I can finish this later--" once he starts on something he wants to do. And it was that way right from the hospital--the minute we moved over into the pediatrics ward he was brought some models-and a-that's the one thing he seemed to want to do--the minute the doctors came in he could hardly talk to the doctors--he didn't want to take his eyes off of it. He was given therapy where he made different things and once he started making them he didn't want to be bothered with anybody else--he didn't want to answer any questions or--it just seems like whatever he's into right at that time it is--it's almost like it's an obsession with whatever he's doing--either that or he turns it off completely.

C: Kind of all or nothing. Does that interfere with his school work?

Ms. X: Oh, I think it does. 'Cause I think lots of times if he thinks he can't master something he just turns it off. Now I know again with some books that we brought home--he had some reading--and it was just--a--looking up words in the dictionary. It was very simple. And it was three stories to read--but it was like 20-25 words to look up. When he first looked at the list, he just closed his book and after--I'd just kinda peak into his room every once in a while--so finally I went in and sat down and I said, "Well, what are some of these words?" And then we started talking about them. Well, then he could give me a fairly good definition even to write down--I said, "Well, why don't we just get the dictionary and see how close you are to the right meaning?" Well, then when we looked it up then he went ahead. I had to get in there and start getting him to look them up--well, then he was fine once he got--once he got started in doing it. But it seems everything is just kind of a push to get him going.

Ms. X also told of her son's inability to plan and organize simple school activities and the increased responsibility which she has assumed as a result.

Ms. X: Yeah that's another thing--see--a couple of times he's had tardies listed on his papers and that was because he didn't get to the class on time and sat down in his seat and the books open before the bell rang--and I think it's just mostly organization--he just didn't organize his books--his tablets--his pencils--there's always something he forgets or he leaves in his locker--or he didn't have it all organized to get to the class in time--and it seems like I'm worrying about extra things--even when I take him to school I'm making sure he has a pencil and paper and things.

C: You become kind of his organizer then do you?

Ms. X: Yeah. I find myself doing that and I keep wondering later on in life--and even when he gets to school--what's he gonna do when I'm not there? I do worry about that--and it makes him mad at me--it's kind of a vicious circle.

Finally, she described what was to become a recurrent theme throughout the interviews. At all levels of high school and college, difficulty was experienced in quantitative subject areas such as science and mathematics.

C: What are the subjects that are most difficult then for him?

Ms. X: Math. Number one. Because he was good in math. He always enjoyed math. I never had to push him to try to study it--and now it just seems like it's a curse. He just--he does not want to study it--he doesn't think he can do it--and he still told the doctor up there when he was being interviewed that was one of his favorite subjects, but after this year and a half of doing poorly in it he's getting so he doesn't like it. He doesn't even wanna talk about math anymore.

This boy's science teacher was also interviewed. She is uniquely qualified to comment because her own son is brain injured and she has had two brain injured students in the same class. She confirmed and supplemented the problems Ms. X described. Both women indicated that Ms. X's son had emotional outbursts which were difficult to handle. His teacher described him as having a brief attention span, limited staying power, and "a short fuse," indicating that when he blew up in school it was "difficult to bring him back down in a 55-minute class." Ms. X revealed similar problems at home. She described emotional swings ranging from flat affect--"He doesn't laugh nearly as much as he used to, and sometimes a whole week will go by when I don't get two smiles from him"--to inappropriate outbursts of anger which make her fear for the safety of his younger sister.

The teacher noted that the pre-trauma characteristics of both of her brain injured students had been exaggerated since their accidents. She expressed concern that such pupils are just "dumped" into schools and that a "buffer zone" is needed between hospitals and schools. She strongly advocated that teachers be trained to work with these pupils, and noted that in her school some teachers had not even been informed that their students had suffered brain injuries.

RECURRENT THEMES

Lost in Space

Often the interviewed students and their families spoke

of a feeling of disorientation upon returning to school after brain injury.

One boy had attended elementary and junior high school in his small home town, but in the months before his accident he had transferred to a large consolidated high school. When, following the accident, he returned to the larger high school, he remembered nothing about it and felt that he had never been a part of it. He subsequently returned to his former school where he was known, felt he belonged, remembered the building, the students, and teachers. Now, more than ever, he needed the security of a familiar setting in order to learn.

In another case, a brain injured high school student was transferred, following his accident, to a different high school in order to receive the special education services his previous school did not provide. His parents reported that although the change was necessary, it was an additional strain on their son. He never accepted the new setting, never felt the loyalty or the "school spirit" that he had felt in his previous school. He was a stranger in a strange environment.

School can be a noisy, confusing learning environment for normal students. It seems close to impossible for volatile, easily distracted students with brain injury. They struggle in a setting where few of their peers and teachers understand the nature of their limitations.

Working More and More on Less and Less

A common belief expressed by teachers, family members, and the brain injured themselves is that "These students could do the work if they would just try harder." At school, teachers and students watch the hours of study increase while grades go down and course after course is eliminated from the schedule. At home, a grandfather becomes frustrated because his grandson no longer retains what he learns in their algebra homework sessions. Eventually, the grandfather discounts him as obstinate and unwilling to try.

At college, a head injured graduate student returns to his graduate fellowship in chemistry to find that he can no longer keep with the rigorous program he loved. He works longer hours, reducing his academic load and his social life, while reaching out for help that is not available. Finally, he drops out of college saying "I used to be a Hoosier Scholar; now I'm a Hoosier Idiot!"

Some evidence is unfolding that teachers may hold two assumptions that work against learning by brain injured students:

1. Harder work will insure success, and
2. More of the same will help. (e.g., more math problems)

What will happen to these students if they get caught up in the current national trends to increase homework, make school days longer and harder, and spend more "time on task"? Most who look normal will be expected to learn accordingly.

Different Isn't Always Wrong

Occasionally, interviews revealed innovative problem solving attempts by the brain injured. These attempts, while often inefficient, are important because they were self-initiated, and in the long run they worked.

A mother said of her son: "Sometimes I wonder why he doesn't just go from A to B. Instead, he goes from A to C and D and then back to B. He seems to have to go all around a problem before he gets back to it."

Another set of parents described their son's attempt to get home from his work at Goodwill Industries. One day he missed his bus and, having spent his emergency money, he thought he could not phone home. He observed the buildings of downtown Indianapolis, remembered that he lived on the other side of those buildings, and set out on foot. After walking several miles, he came upon a police station, where he was given change to call his parents. It was a long walk to a solution, but it was his solution, and it got him to his destination.

It seems important that each person who helps the brain injured learn to solve problems remain open to the systems which they utilize, even the inefficient ones--especially when they work.

Helping Without Hurting

Brain injured learners need advocates in the schools. Parents interviewed indicated that they are sometimes reluctant to intervene on behalf of their kids. They were either unaware that they have a legal right to insist upon appropriate services for school age children or they were unwilling to intervene in a system that they assumed was already doing the best it could.

Some felt that it was inappropriate to ask for additional help when they didn't know what kind of help to ask for. Others didn't know who to ask, or who to tell, about their child's condition.

Schools are sometimes very rigid systems. When parents are unfamiliar with the system, intervention is difficult. Even those who do understand the system find that implementing change is difficult.

One phone call came from a rural Indiana speech therapist who is employed by the school system attended by her brain injured son. She knew her school system well enough to know that the help her son needed was not being provided--and was probably not even available locally. She was afraid to fight for what was needed for fear that she, her job, and her son might suffer repercussions.

Other mothers reported being labelled as "overprotective" and "interfering", which they may well be. They know that their

children are in trouble academically and socially. They don't know where to turn for help or how much to push for what they need.

And help is particularly needed for the thousands of brain injured students who make abrupt transitions from hospitals and/or rehabilitation facilities to homes and schools. Most are young; and they are disproportionately high school and college age males. They are part of a broad problem described as "epidemic" by the National Head Injury Foundation. (Spivack, 1984).

Upon returning to academia, they must face educators who have little or no preparation directed toward their needs. Even special education teachers, learning disability specialists, and speech therapists are just beginning to learn about the phenomenon. So where is the needed help?

POSSIBLE SOLUTIONS

Transition to School

The sheer magnitude of the brain injury problem of school/college students provides a discouraging picture to overextended rehabilitation specialists. They must deal with insurance companies and social agencies that often contribute to a revolving door atmosphere in which brain injured youth are prematurely sent home to attend regular school and attempt readjustment to normal life situations. Few rehabilitation facilities have the opportunity to provide a complete and accredited school within

their institution, although such a program is provided by the Rehabilitation Institute of Pittsburgh. (Ylvisaker, et al., 1983).

An interesting transitional model is provided by the Gillette Children's Hospital in St. Paul, Minnesota. School personnel who will be expected to work with specific brain injured pupils are invited to biweekly family conferences for two months prior to the injured pupil's return to school. Recovery is observed. As families and teachers learn that the situation is not static, they more realistically prepare for the patient's return to home and school. When a pupil does return, therapists and other hospital staff again meet with school personnel. A videotape of the returning student is shown to classmates and teachers, opening dialogue for mutual problem solving with the aid of the rehabilitation team. The Gillette model is attractive in its apparent simplicity, economy, and effectiveness. (Sellars, et al., 1983).

Sources of Help

At least four large groups of people can provide leverage to help brain injured students achieve their social and educational potentials. Perhaps the most important are parents and family members. They are available daily, care deeply, and have great influence over long term recovery and development. It is important that parents be recognized for their contributions to gains made in therapy and at school. They can be utilized to observe and record behaviors. They can be given information, free of professional jargon, to help them understand the

potential and the limitations of their injured family member. In return, they will inform others who are involved with their loved one.

Educators are an obvious but not yet fully utilized resource. Most are altruistic, experienced teachers whose roles are inherently the cognitive development of youth. Given an awareness of the special problems of brain injured students, they become significant members of the support team. Some, notably learning disability teachers and speech therapists, may already have basic knowledge of the learning problems of the brain injured. By increasing and updating their knowledge through exposure to recent literature, participation in workshops, and exchange of information with rehabilitation therapists specializing in traumatic head injury, educators can become even more effective teachers of the brain injured.

Rehabilitation specialists are, perhaps, the resource group most overlooked. Cognitive and speech therapists from rehabilitation settings should be encouraged to brief educators on what they have learned from their work with surviving head trauma patients in the past decade.

Briefings may be most effective when begun in training institutions with teacher educators, administrators, school psychologists, and others who can effect change. The multiplier effect is needed; a few can positively influence many.

A fourth source of assistance to brain injured students is that group of individuals who know and can utilize the

myriad legal precedents that relate to educational opportunity and the handicapped. Public Law 94-142 requires that each handicapped child receive an individualized education program (IEP) to include specific education and related services. The law's subpart definitions include brain injury under "Specific Learning Disability," (Hanson and Penrod, 1980). Federal courts have cited the Fifth Amendment and the Civil Rights Act, among other authorizations, in holding that school districts must provide a free and suitable publicly-supported education regardless of the degree of the child's mental, physical, or emotional disability or impairment. There are legal precedents to support cases related to executive function difficulty, as in the case No. 10919, SEA NY, 1982, where evidence other than neurological test results confirmed the need for special education in a least restrictive environment. (Education for the Handicapped Law Report, 1983).

Bureau of the Handicapped (BEH) rulings state:

> Reg. 300.532(e) and 300.540(b) require that evaluation team evaluating child suspected of having learning disability include "at least one teacher or other specialist with knowledge in the area of suspected disability", as well as "licensed, certified, or approved specialists" and additional qualified personnel where appropriate or necessary. (DAS Bulletin No. 9, 1978).

This allows a rehabilitation specialist to work along with educators and family members to create and monitor the Individualized Education Program which is legally required for each brain injured student.

Through helping organizations like the National Head Injury Foundation and its state/regional affiliates, rehabilitation specialists can join educators and families in common goals. Gaps can be bridged when these goals are set and professionals work together.

Brain injured students need informed, systematic, and continuing assistance in order to succeed socially and educationally. As one of the teachers interviewed asked, "How do you teach head injured kids? How do they turn out as adults?" The search for answers continues.

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Selected Sources of Information and Materials

for Utilization with Head Injured Learners

National Head Injury Foundation, Inc.
18A Vernon Street
Framingham, MA 01701 Ph. (617) 879-7473

Contact for list of publications, address of state/local support group; names of area resource persons.

Cognitive Rehabilitation (journal)
3157 Stillmeadow
Indianapolis, IN 46224 Ph. (317) 291-5809

Editor, Dr. Odie Bracy, also develops software for re-education of head injured youth.

Center for Neuropsychological Rehabilitation
Suite 100, 7155 Shadeland Station
Indianapolis, IN 46250 Ph. (317) 845-8128

Center Director, Dr. Lance E. Trexler, also directs the annual International Symposium on Cognitive Rehabilitation held in Indianapolis each Spring.

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